

7. **People with IBS don't talk about it very much.** There is nothing a person with IBS would love more than to only have to explain their health condition, and their health needs, once and only once. Unfortunately, most people don't get it the first time. Or they think it's just a temporary problem that will go away by next time. And so IBS sufferers find themselves having to bring up the subject the next time... and the next time.
8. **People with IBS are not obsessed with their bowels.** Have you ever heard of an asthma sufferer who was trying to explain their condition being called "*respiratory obsessed*"? And you'd never hear of someone describing their heart condition being called, "*cardiovascularly obsessed*". But because our GI systems are such a taboo subject, people who try to explain their GI problems are labeled, "*bowel obsessed*", and sometimes by their own doctors!
9. **IBS is not contagious.** I'm not going to make you sick. And if I'm in a relationship with you I still need you to hug me and love me.
10. **IBS is not "all in our heads".** It's true that stress can compound the symptoms, but the "all in my head" routine makes us feel like we're being called crazy. Believe us, we're not crazy, we're just not feeling well.
11. **There are many IBS symptoms.** Some not even related to sitting on the toilet. And for many people with IBS, the symptoms are frequently changing.
12. **Don't take my condition personally.** Just because I don't want to go out doesn't mean I don't want to spend time with you. I can't always go places where there are no bathrooms, but maybe we could go someplace that does.
13. **I can't always help being late.** If I'm late, it's not because I didn't plan or didn't care, I just can't help it. If I'm not where I said I'd be when I was supposed to, I might be around the corner in the bathroom, but trying to get there.
14. **I can't control how often I get sick.** And if I wasn't putting in a constant effort to keep my symptoms toned down, I would be getting sick even more often. Please don't make me feel worse than I already do by accusing me of "*always being sick*".
15. **Sometimes the only thing that helps is space.** If I don't feel like being with anybody, that means *anybody*, not just you.
16. **It's not funny when you have to live with it every day.** You know, everyone should be able to laugh at themselves, but there is a limit. To quote someone from the IBS Bulletin Board, "*If I hear another 'spastic colon' joke I may totally lose it!*" Sometimes the best way to show a little compassion, is to show a little tact.

## Thanks for your understanding

Thanks for taking the time to read this brochure and for understanding what it's like to live with Irritable Bowel Syndrome. Whether you are a family member, friend, or co-worker of someone with IBS, your understanding is very important to them.

When a person develops IBS, their body becomes a very difficult place to live in. By taking the time to understand IBS, you have helped to make their environment an easier place to live in.



**YOU DON'T HAVE TO COPE ALONE**  
Join us on-line at [www.ibsgroup.org](http://www.ibsgroup.org)

# What is Irritable Bowel Syndrome?

An easy-to-read pamphlet for people who do not have IBS  
written by 'Molly', and designed by 'e-fiona', members of the IBS Self-Help Group Web Site  
[www.ibsgroup.org](http://www.ibsgroup.org)

When my doctor informed me that I had IBS, I thought all my problems were over. At last! There was an actual reason why I was experiencing all those miserable symptoms. Symptoms that ranged from inconveniencing to incapacitating. Symptoms that didn't follow any rules and could pop up at any time of day to throw a monkey wrench in a plan, or ruin a social event. Well, all those icky medical tests were worth it because the mystery was over. Let the curing begin!

Then I asked my doctor what IBS was. He told me it stood for Irritable Bowel Syndrome.

"How exciting", I said. "And what is that exactly?"

He said, "*IBS is a functional bowel disorder of the gastrointestinal (GI) tract, characterized by abdominal pain and alterations in diarrhea and/or constipation.*"

A diagnosis of IBS has been reported by 10 to 20% of adults and symptoms of IBS are responsible for over 3 million yearly visits to physicians. Research suggests that IBS is one of the most common functional GI disorders.

IBS exhibits a predominance in women, representing over 70% of IBS sufferers.

Irritable Bowel Syndrome is the catch-all diagnosis that is given to people who are experiencing symptoms, usually chronic, with their gastro-intestinal system that are not being caused by a known GI condition or disease. A large percentage of people who suffer from IBS have found that they can't cure it, or make it go away. The best they can do is make changes, through trial and error, in their diets and lifestyle to tone down the symptoms as much as possible.



IBS Self Help and Support Group

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## Don't worry, we're sparing you the details!

Now, you're probably thinking, "Ooooh, I want to hear the details of those symptoms about as much as I want to hear my mother describe going into labor with me." Relax. We

want to *tell you* the details of our symptoms about as much as we want to hear your mother describe going into labor with you. This brochure is not about IBS symptoms, it's about how living with these symptoms impacts a person's life.

Besides, there isn't enough room in this brochure. Two people who have both been diagnosed with IBS could be experiencing symptoms that are exactly the opposite from each other. One of them might only be able to eat certain types of foods that, if the other person ate them, would trigger a severe IBS attack. One of the frustrations and dangers of having IBS is that whenever you get advice, there's a real chance that it could be bad advice for you. IBS is not a true diagnosis, it's a catch-all term the medical community uses when they've ruled out everything else. And it really should stand for, "I'm Basically Stumped".

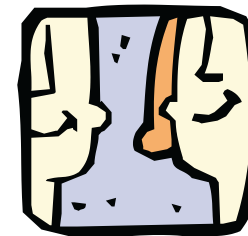
## What this brochure is

One thing that most IBS sufferers have in common is that it's hard to communicate to the people in their life about what it's like to live with IBS. There are several reasons for this. First of all, talking about problems with your GI system is socially taboo. I mean, yuck! It's a topic you'd associate with an infantile comedy routine, not with a conversation between two co-workers, or two people out on a first date. Second, like many chronic conditions, it changes how a person gets through their day. It makes simple daily routines, like going to the bathroom, or ordering food, complicated and difficult. And different. And when your day is different from everyone's around you, it can be very isolating and hard to explain.



Unfortunately, people with IBS often find that they have to explain over and over again. In restaurants, in the office, on trips, and at home. Because even though 20% of the population suffer from some form of GI difficulty, the other 80% have a mental block about believing that it's really real. Or that it's really as bad as people say; that there's a genuine difference between having a 'bad stomach' for a few days and having a chronic condition that effects your whole life.

## The top 5 list



This brochure was put together with feedback from an IBS Self Help Group website. A question was posted on the IBS Bulletin Board, "What are the top five things you wish people who didn't have IBS could understand?" The following list has more than five items, but many people listed similar things and agreed with what other people posted.

As you read this list, please keep in mind that whoever gave you this brochure didn't do it to accuse you of everything on this list. They gave you this brochure to communicate with you the day-to-day issues of living with IBS. It's an embarrassing condition to describe, and it's a difficult lifestyle to explain. This brochure is a way of helping you to help whoever gave you this brochure find ways to live as normal an uncomplicated lifestyle as possible: To not let IBS run their life, or ruin it.

1. **IBS is a high maintenance condition.** You can't simply take a pill and make it go away. And it takes a constant effort to keep it from getting worse. Things like questioning a waiter about the ingredients of every dish or always checking to make sure there is a bathroom nearby may seem like an inconvenience. But they're nothing compared to the inconvenience of triggering an IBS attack because you ate the wrong food, or not being able to get to a bathroom in time.
2. **IBS is not temporary.** It's not something you get over in a few days or even weeks. You may never get over it.
3. **I'm not a picky eater.** I just don't want to get sick. Please don't push me to eat foods I have already said "no thanks" to. I know what my stomach can and can't handle.
4. **When I'm having an attack, I need space.** Please give me my space when I'm in the bathroom. I appreciate your concern, but you can't help, and your hovering just compounds my embarrassment.
5. **The rules are always changing.** And so are the symptoms. Medicines, or herbs, or a special diet that was helping to keep a person's IBS symptoms toned down may suddenly stop working. New symptoms often appear out of nowhere. Foods that didn't bother a person with IBS for years could suddenly trigger a vicious attack. One of the reasons IBS is so difficult to explain is that it keeps changing.
6. **I'm not using IBS as an excuse not to do things.** Making plans to go out can be really scary when the symptoms (and the rules) can change at anytime. Please respect that there are times when I can't go out, even if I want to. And please don't look at me funny when I ask if the place we're going to has a bathroom. Understand that this condition is completely unpredictable. If we go out together, be prepared for me to run off at any moment to find a bathroom.